NCIN Roadshow: Cancer Data

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National Cancer Registration Service (NCRS)

- **Records date back to the early 1950's**

- **Population of 53 million across England**

- **Expected 350,000 registrations for 2014 diagnosis year**

- **8 Regional Branches**

- **Migration to ENCORE in 2009**

- **Cancer Outcomes and Services Dataset in 2013**

NATIONAL CANCER REGISTRATION
Service Overview

HEALTHCARE PROVIDERS

170

Data comes from all acute trusts and a range of healthcare / private providers.

MULTI-DISCIPLINARY TEAMS (MDT)

1,700+

LOCAL DATA SYSTEMS

500+

DATA SOURCES

15

Data sources (diamonds, left to right):
- TRUST PAS / PBR
- COSD / MDT
- PATHOLOGY
- RADIOLOGY
- RADIOTHERAPY
- CHEMOTHERAPY (SACT)
- CANCER WAITING TIMES
- DEATH CERTIFICATE (ONS)
- NATIONAL SCREENING
- PROSTATE AUDIT
- NBOCAP
- LUCADA
- NOGCA
- DAHNO
- BAUS
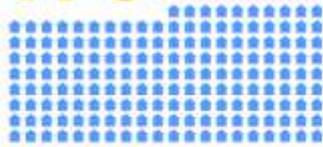
- **LOCAL PROCESS / SYSTEM**
- **OTHER NATIONAL REPOSITORY**
- **NATIONAL AUDIT**

DATA ITEMS PER CASE

UP TO **450**

LOCAL OFFICES

8

The change from a traditional cancer registry to a national registration service significantly increases the value of the resource.

DATA LIAISON

A team working with each provider to ensure that the burden of data collection is minimal.

LONDON	SOUTH WEST	NORTHERN AND YORKSHIRE	NORTH WEST	EASTERN	WEST MIDLANDS	EAST MIDLANDS	OXFORD
75,113	66,210	49,537	49,119	42,050	41,202	37,328	18,896
41	23	20	28	18	20	11	9

ANNUAL REGISTRATIONS

343,187*

*2012 PI FIGURES (UKIACR)

New tumours diagnosed (finalised cases only) each year from the entire 52 million population of England.

Public Health England
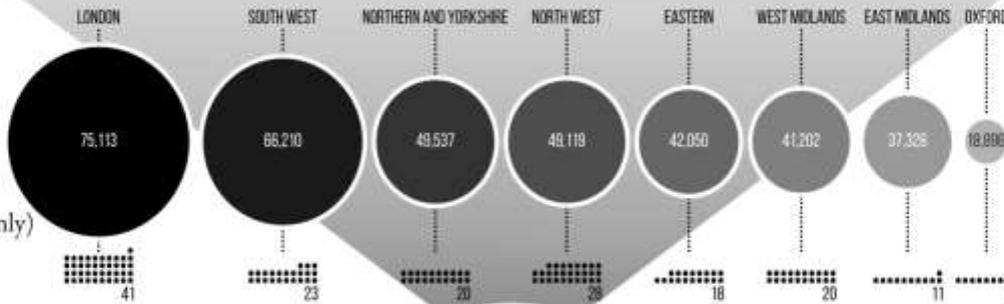
HISTORICAL RECORDS

11 MILLION

ENCORE

WORLD CLASS SERVICE

The National Cancer Registration Service and the dataset that it collects is now the largest, most detailed and timely cancer data collection system anywhere in the world.

Datasets & Data Collection

Understanding Data Flows in the NCRS
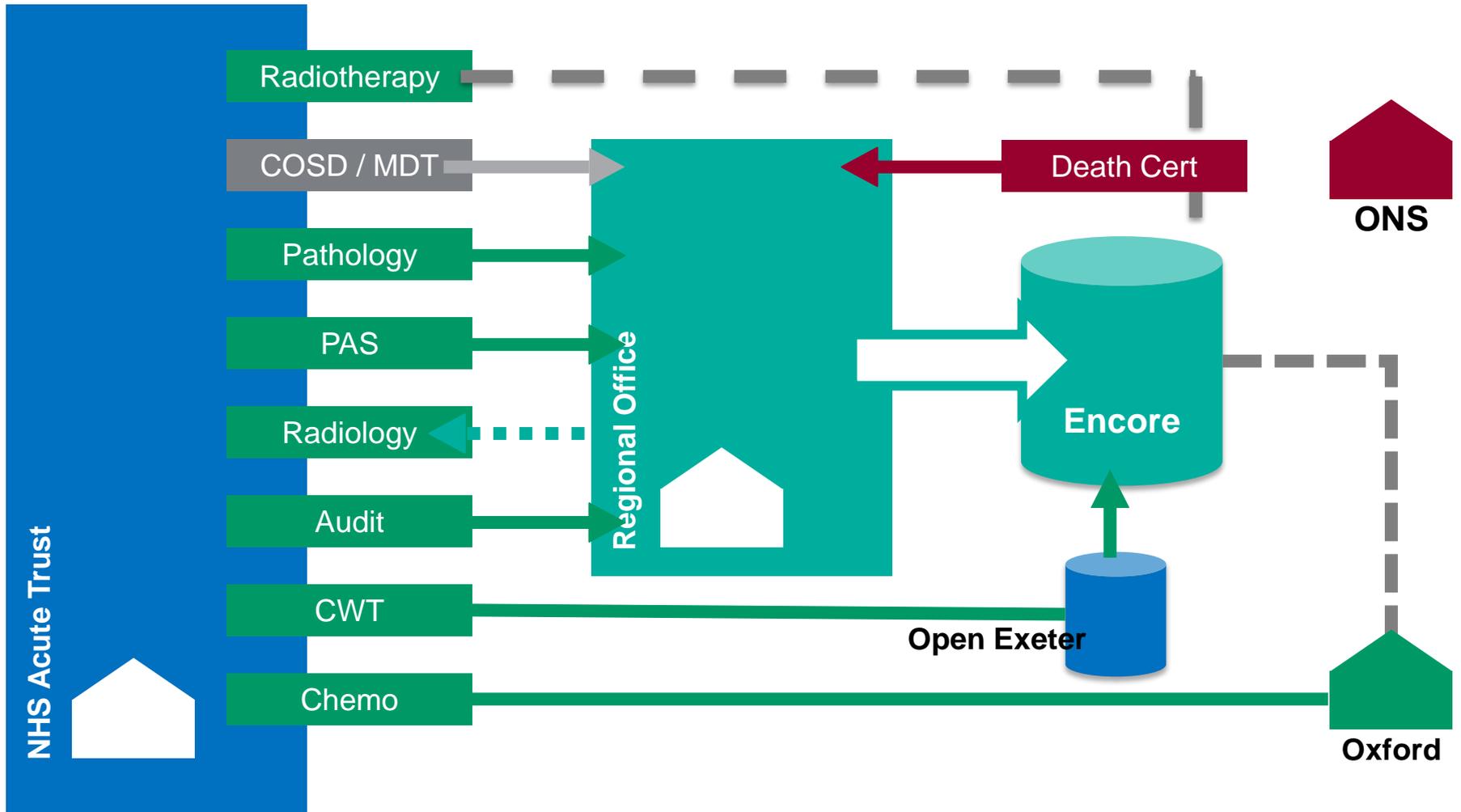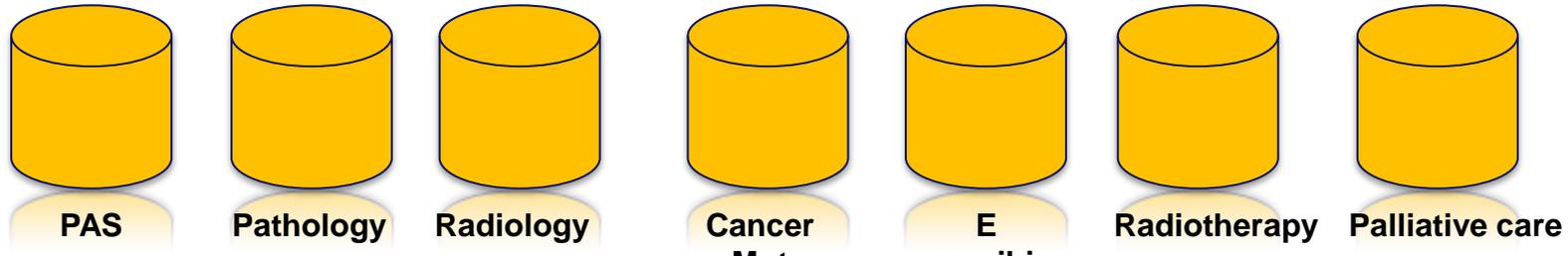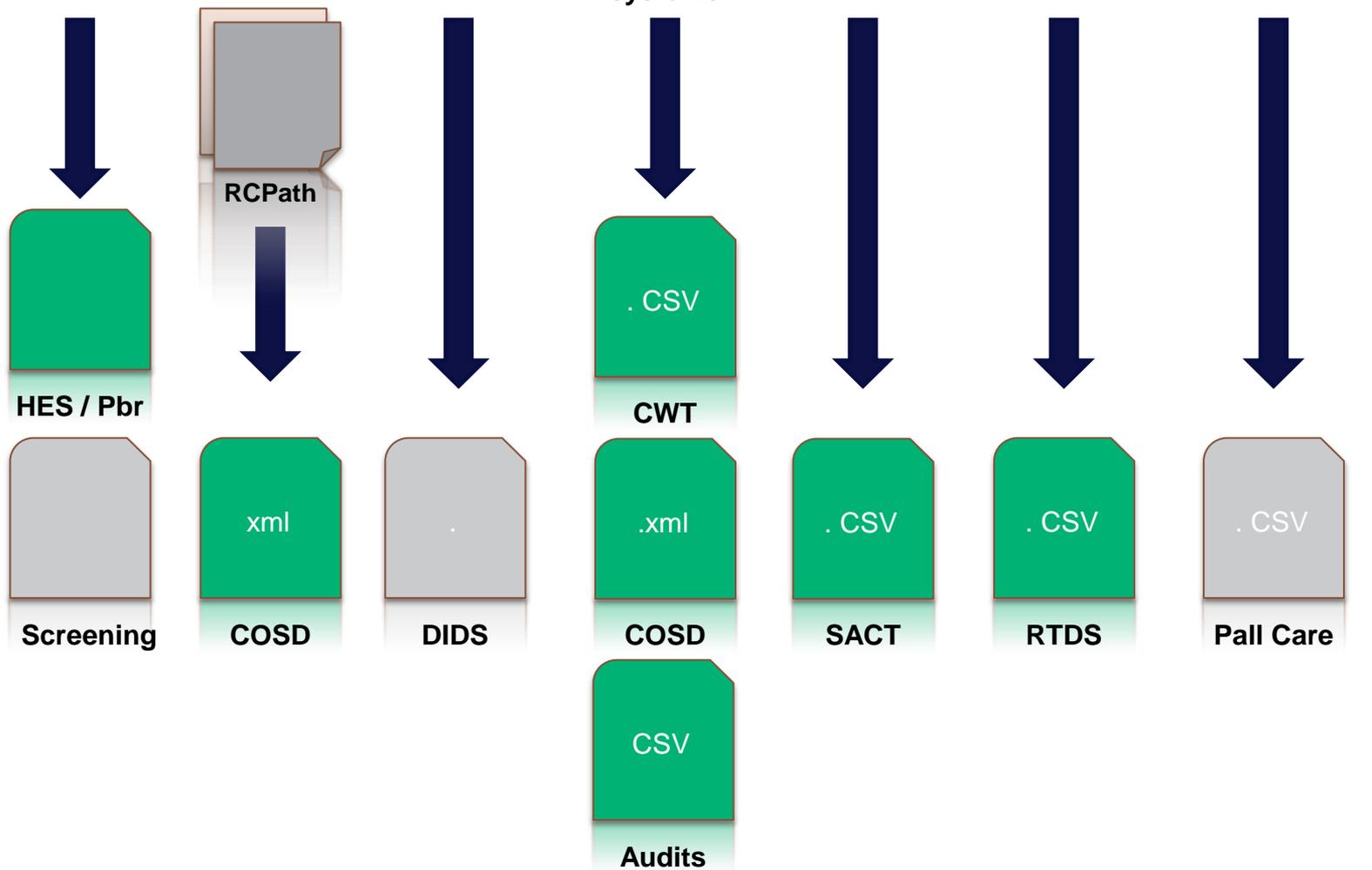
Chemotherapy (SACT) & Radiotherapy (RTDS)

Systemic Anti-Cancer Therapy (SACT)
- The Chemotherapy Intelligence Unit (CIU) commissioned in 2011 by NCIN to create and manage a repository for cancer chemotherapy data in England
- The CIU are a central collation point for all data submissions in England
- The CIU are responsible for management and QA of the data as well as providing support all submitting units
- The CIU also provide an analytical function in the form of regular clinically approved reports available to key stakeholders

National Radiotherapy Dataset
- From 1st April 2009, all facilities providing radiotherapy services were mandated to return the RTDS to National Clinical Analysis and Specialised Applications Team (NATCANSAT)
- The purpose is to collect consistent and comparable data across 50 Radiotherapy Centres in England
- This will enables analysis and intelligence for service planning, commissioning, research and the provision of Radiotherapy services across England
- From April 2016 this will be now managed by PHE in collaboration with the NCRS
- The linkage of COSD, RTDS and SACT within PHE, will allow a more timely and comprehensive review of treatment pathways and associated outcomes

Cancer Waiting Times (CWT)

- Cancer Waiting Times standards monitor the length of time that patients with cancer or suspected cancer wait to be seen and treated in England
- First introduced through the NHS Cancer Plan in September 2000

Upcoming Changes
- Version 9 of the Cancer Waiting Times: A Guide is being updated.
- There will be two new data items from March 2016 onwards:
    - NHS NUMBER STATUS INDICATOR CODE
    - REFERRAL REQUEST RECEIVED DATE (INTER-PROVIDER TRANSFER).
- Data submissions are also set to change from CSV to XML submissions from March 2016.

Useful Links
The **quarterly reports** can be found:
http://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/

Guidance documents can be found:
http://nww.hscic.gov.uk/nhais/cancerwaiting/documentation.
> **Cancer Waiting Times: A Guide — Version 8.0**
> **National Cancer Waiting Times User Manual - v6.1**
> **National Cancer Waiting Times Reports User Manual - Version 1.0**

National Audits: Key Points

- **Lung Cancer Audit** - Contract awarded to Royal College of Physicians in partnership with NCRS from 1 December 2014
  - Renamed National Lung Cancer Audit (NLCA)
  - Will utilise COSD as its primary data source
  - Feedback on completeness to trusts May 2015
  - Annual Report December 2015

- **Colorectal Cancer Audit** – Ongoing contract with Royal College of Surgeons with the Health Social Care Information Centre (HSCIC)

- **Head & Neck Cancer Audit** - Contract awarded to Saving Faces - The Facial Surgery Research Foundation from 1 July 2015
  - Renamed Head and Neck Cancer Audit (HANA).

- **Upper GI Cancer Audit** - Ongoing contract with HSCIC until 2016

National Audits: Key Points

Public Health England

- **Prostate Cancer Audit -** Began in 2014 contract awarded to Royal College of Surgeons' Clinical Effectiveness Unit (CEU) in partnership with NCRS
  - Near real time data collection from MDT's
  - Data set largely collected as part of routine flows
  - NCRS produces linked audit datasets for analysis
  - Feedback and Completeness reports available on CancerStats Portal

- **Breast Cancer Audit –** Healthcare Quality Improvement Partnership (HQIP) launched Procurement for the new audit on 13th April 2015

The Diagnostic Imaging Dataset (DID)

Public Health England

- Record-level data from NHS Radiology Information Systems (RIS) relating to diagnostic imaging activity in hospitals in England.

- Health and Social Care Information Centre (HSCIC) collect data on a monthly basis. It is linked to Hospital Episodes Statistics for fuller analysis.

- NHS users may apply for access to the DID via HSCIC's iView reporting tool. Details of this and the collection are at: http://www.hscic.gov.uk/DID

- Results are analysed and published by NHS England in provisional monthly summary reports and a final annual release, at:

  http://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/

Cancer Outcomes & Services Dataset 2013

Public Health England

- **Phased Rollout:** January 2013 – January 2015

- **New Dataset:** Incorporating Registration Data

- **Aligned and Rationalised with Other Cancer Datasets**

- **Core Data Set and Site Specific Items**

- **Intended to Record Key Data from the Entire Patient Pathway**

- **Requires Monthly Submission from Trusts**

- **Recent Implementation of Feedback and Quality Reporting Back to Trusts**

- **RCPath aligning with COSD**

NCRS CancerStats Portal

COSD Level 1 Reports

COSD Level 2 – 2015 Staging Completeness

L2.1j - Number of Cancers with a Full Stage at Diagnosis
Report Generated: October 11th, 2015

	Total Stageable Cases	Total Staged	% Staged	National Ranking
Medway NHS Foundation Trust (RPA)	1453	1036	71.3%	31
Dartford and Gravesham NHS Trust (RN7)	904	631	69.8%	35
Maidstone and Tunbridge Wells NHS Trust (RWF)	2274	1317	57.9%	67
East Kent Hospitals University NHS Foundation Trust (RVV)	2517	1368	54.4%	74
Queen Victoria Hospital NHS Foundation Trust (RPC)	561	64	11.4%	150
Surrey and Sussex Healthcare NHS Trust (RTP)	1612	592	36.7%	113
Frimley Park Hospital NHS Foundation Trust (RDU)	1251	444	35.5%	118
Ashford and St Peter's Hospitals NHS Foundation Trust (RTK)	1039	203	19.5%	139
Royal Surrey County NHS Foundation Trust (RA2)	3188	440	13.8%	148
Western Sussex Hospitals NHS Foundation Trust (RYR)	2880	1956	67.9%	44
Brighton and Sussex University Hospitals NHS Trust (RXH)	2476	1142	46.1%	93
East Sussex Healthcare NHS Trust (RXC)	1860	498	26.8%	131

COSD Conformance Summary Level 2

L2.1j - Number of Cancers with a Full Stage at Diagnosis

Report Generated: September 12th, 2015

	Total Stageable Cases	Total Staged	% Staged	National Ranking
Homerton University Hospital NHS Foundation Trust (RQX)	425	374	88%	1
Royal Free London NHS Foundation Trust (RAL)	777	682	88%	2
Royal Devon and Exeter NHS Foundation Trust (RH8)	2164	1898	88%	3
Papworth Hospital NHS Foundation Trust (RGM)	332	285	86%	4
Wrightington, Wigan and Leigh NHS Foundation Trust (RRF)	1048	905	86%	5
St George's Healthcare NHS Trust (RJ7)	1138	952	84%	6
Chesterfield Royal Hospital NHS Foundation Trust (RFS)	1002	818	82%	7
Liverpool Heart and Chest NHS Foundation Trust (RBQ)	823	662	80%	8
Blackpool Teaching Hospitals NHS Foundation Trust (RXL)	1328	1047	79%	9
Royal Liverpool and Broadgreen University Hospitals NHS Trust (RQ6)	1312	1028	78%	10
Ipswich Hospital NHS Trust (RGQ)	1248	977	78%	11
St Helens and Knowsley Hospitals NHS Trust (RBN)	1542	1194	77%	12
Stockport NHS Foundation Trust (RWJ)	950	721	76%	13
Wirral University Teaching Hospital NHS Foundation Trust (RBL)	1341	1009	75%	14
Hinchingbrooke Health Care NHS Trust (RQQ)	493	369	75%	15
The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust (RCX)	947	708	75%	16
Royal National Orthopaedic Hospital NHS Trust (RAN)	238	179	75%	17
Kingston Hospital NHS Foundation Trust (RAX)	760	563	74%	18
Imperial College Healthcare NHS Trust (RYJ)	1295	954	74%	19
The Hillingdon Hospitals NHS Foundation Trust (RAS)	586	431	74%	20
Bridgewater Community Healthcare NHS Trust (RY2)	97	70	72%	21
Bedford Hospital NHS Trust (RC1)	844	610	72%	22
Medway NHS Foundation Trust (RPA)	1056	756	72%	23
Hampshire Hospitals NHS Foundation Trust (RN5)	1358	978	72%	24
Dorset County Hospital NHS Foundation Trust (RBD)	1066	770	72%	25

2015 Staging Completeness - Top 25 National Ranking

Public Health England

L2.1j - Number of Cancers with a Full Stage at Diagnosis
Report Generated: October 11th, 2015

	Total Stageable Cases	Total Staged	% Staged	National Ranking
Homerton University Hospital NHS Foundation Trust (RQX)	486	433	89.1%	1
Royal Devon and Exeter NHS Foundation Trust (RH8)	2528	2225	88.0%	2
Wrightington, Wigan and Leigh NHS Foundation Trust (RRF)	1190	1032	86.7%	3
Papworth Hospital NHS Foundation Trust (RGM)	379	328	86.5%	4
Royal Free London NHS Foundation Trust (RAL)	914	782	85.6%	5
Chesterfield Royal Hospital NHS Foundation Trust (RFS)	1002	818	81.6%	6
St George's Healthcare NHS Trust (RJ7)	1517	1221	80.5%	7
Liverpool Heart and Chest NHS Foundation Trust (RBQ)	823	662	80.4%	8
Blackpool Teaching Hospitals NHS Foundation Trust (RXL)	1526	1214	79.6%	9
Royal Liverpool and Broadgreen University Hospitals NHS Trust (RQ6)	1476	1163	78.8%	10
Ipswich Hospital NHS Trust (RGQ)	1426	1112	78.0%	11
St Helens and Knowsley Hospitals NHS Trust (RBN)	1794	1396	77.8%	12
Stockport NHS Foundation Trust (RWJ)	1097	839	76.5%	13
Hinchingbrooke Health Care NHS Trust (RQQ)	570	434	76.1%	14
Royal National Orthopaedic Hospital NHS Trust (RAN)	238	179	75.2%	15
The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust (RCX)	1067	801	75.1%	16
Harrogate and District NHS Foundation Trust (RCD)	765	573	74.9%	17
Kingston Hospital NHS Foundation Trust (RAX)	864	644	74.5%	18
Wirral University Teaching Hospital NHS Foundation Trust (RBL)	1833	1364	74.4%	19
Bridgewater Community Healthcare NHS Trust (RY2)	105	78	74.3%	20
Bedford Hospital NHS Trust (RC1)	961	712	74.1%	21
Imperial College Healthcare NHS Trust (RYJ)	1298	957	73.7%	22
The Hillingdon Hospitals NHS Foundation Trust (RAS)	684	496	72.5%	23
East Lancashire Hospitals NHS Trust (RXR)	1814	1313	72.4%	24
The Royal Orthopaedic Hospital NHS Foundation Trust (RRJ)	105	76	72.4%	25

2015 Staging Completeness - Bottom 25 National Ranking

L2.1j - Number of Cancers with a Full Stage at Diagnosis
Report Generated: October 11th, 2015

	Total Stageable Cases	Total Staged	% Staged	National Ranking
Bradford Teaching Hospitals NHS Foundation Trust (RAE)	1603	383	23.9%	134
University Hospitals North Midlands (RJE)	2790	641	23.0%	135
Mid Essex Hospital Services NHS Trust (RQ8)	1864	419	22.5%	136
University Hospital Birmingham NHS Foundation Trust (RRK)	3150	691	21.9%	137
Shrewsbury and Telford Hospital NHS Trust (RXW)	2292	470	20.5%	138
Ashford and St Peter's Hospitals NHS Foundation Trust (RTK)	1039	203	19.5%	139
Alder Hey Children's NHS Foundation Trust (RBS)	27	5	18.5%	140
United Lincolnshire Hospitals NHS Trust (RWD)	1324	242	18.3%	141
County Durham and Darlington NHS Foundation Trust (RXP)	1562	284	18.2%	142
Sheffield Children's NHS Foundation Trust (RCU)	11	2	18.2%	143
South Warwickshire NHS Foundation Trust (RJC)	412	70	17.0%	144
Oxford University Hospitals NHS Trust (RTH)	2404	379	15.8%	145
Salford Royal NHS Foundation Trust (RM3)	559	84	15.0%	146
Walsall Healthcare NHS Trust (RBK)	621	87	14.0%	147
Royal Surrey County NHS Foundation Trust (RA2)	3188	440	13.8%	148
North Cumbria University Hospitals NHS Trust (RNL)	1013	122	12.0%	149
Queen Victoria Hospital NHS Foundation Trust (RPC)	561	64	11.4%	150
Royal Berkshire NHS Foundation Trust (RHW)	1586	170	10.7%	151
East and North Hertfordshire NHS Trust (RWH)	1933	195	10.1%	152
Birmingham Children's Hospital NHS Foundation Trust (RQ3)	45	3	6.7%	153
Moorfields Eye Hospital NHS Foundation Trust (RP6)	71	1	1.4%	154
The Clatterbridge Cancer Centre NHS Foundation Trust (REN)	0	0	0.0%	155
The Walton Centre NHS Foundation Trust (RET)	13	0	0.0%	156
Great Ormond Street Hospital for Children NHS Foundation Trust (RP4)	14	0	0.0%	157
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust (RL1)	0	0	0.0%	158

2015 Staging Completeness - By Strategic Clinical Network

L2.1j - Number of Cancers with a Full Stage at Diagnosis
Report Generated: October 11th, 2015

	Total Stageable Cases	Total Staged	% Staged
Cheshire And Mersey	10666	7786	73%
East Midlands	14705	5769	39%
East Of England	27501	12255	45%
Greater Manchester, Lancashire & South Cumbria	22231	14444	65%
London Cancer	10831	5940	55%
London Cancer Alliance	15126	9657	64%
North East. North Cumbria, And North Yorks	16048	6738	42%
South East Coast	22015	9691	44%
South West	25181	13032	52%
Thames Valley	7627	1808	24%
Wessex	12205	6795	56%
West Midlands	22729	8617	38%
Yorkshire And The Humber	27103	11721	43%
Total	**233968**	**114253**	**49%**

Public Health England

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COSD Level 3 Reports

L3.1a: Total Number of Diagnoses

Single Pathway

These counts show patients whose complete pathway is restricted to a single trust. It can therefore be assumed that this trust would be fully responsible for the collection of all COSD data items.

Shared Pathway

These counts show patients whose pathway has been partially handled by the trust, but who has also visited other trusts. At the end of the trust summary report for Level 3, there is a breakdown of the trusts which have handled the shared pathway patients.

L3.1b: Basis of Diagnosis

L3.1c: Clinical Nurse Specialist Indication Code

Export ▾

	2013												
	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
L3.1a - Total Number of Diagnoses	429	48	31	49	47	38	31	27	22	32	31	41	32
Single Hospital Pathway	269	31	18	31	28	18	20	17	16	19	23	30	18
Shared Hospital Pathway	160	17	13	18	19	20	11	10	6	13	8	11	14
L3.1b - Basis of Diagnosis	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
✚ Clinical	97	9	7	12	9	8	9	4	5	8	11	6	9
✚ Histology	330	39	24	37	37	30	22	23	16	24	20	35	23
✚ Unknown	2	0	0	0	1	0	0	0	1	0	0	0	0
L3.1c - Clinical Nurse Specialist Indication Code	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Yes, including nurse present when patient given diagnosis	1	0	0	0	0	0	1	0	0	0	0	0	0
Yes, but nurse not present when patient given diagnosis	1	0	0	0	0	0	0	0	0	1	0	0	0
Not received	427	48	31	49	47	38	30	27	22	31	31	41	32
L3.1d - Age at Diagnosis	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
✚ 25-44	2	0	1	0	0	0	0	0	0	0	0	1	0
✚ 45-64	90	14	6	13	4	8	6	6	6	4	5	9	9
✚ 65-84	276	29	18	30	36	27	18	21	14	23	21	20	19
✚ 85+	61	5	6	6	7	3	7	0	2	5	5	11	4

COSD Level 3 Reports

L3.1a: Total Number of Diagnoses

Single Pathway

These counts show patients whose complete pathway is restricted to a single trust. It can therefore be assumed that this trust would be fully responsible for the collection of all COSD data items.

Shared Pathway

...have handled the shared pathway patients.

L3.1b: Basis of Diagnosis

L3.1c: Clinical Nurse Specialist Indication Code

Export ▾

	2013												
	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
L3.1a - Total Number of Diagnoses	429	48	31	49	47	38	31	27	22	32	31	41	32
Single Hospital Pathway	269	31	18	31	28	18	20	17	16	19	23	30	18
Shared Hospital Pathway	160	17	13	18	19	20	11	10	6	13	8	11	14

Callout (enlarged):

	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
L3.1a – Total Number of Diagnoses	429	48	31	49	47	38	31	27	22	32	31	41	32
Single Hospital Pathway	269	31	18	31	28	18	20	17	16	19	23	30	18
Shared Hospital Pathway	160	17	13	18	19	20	11	10	6	13	8	11	14

L3.1d - Age at Diagnosis:

	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
25-44	2	0	1	0	0	0	0	0	0	0	0	1	0
45-64	90	14	6	13	4	8	6	6	6	4	5	9	9
65-84	276	29	18	30	36	27	18	21	14	23	21	20	19
85+	61	5	6	6	7	3	7	0	2	5	5	11	4

COSD Level 3 Reports

L3.1e - Multi-Disciplinary Team (MDT) Indicator	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Discussed at MDT	210	31	18	29	15	19	13	11	14	18	16	15	11
Not Discussed at MDT	93	4	4	5	11	7	10	8	5	10	6	14	9
Not Known	126	13	9	15	21	12	8	8	3	4	9	12	12
L3.1f - Performance Status at Diagnosis	**Total**	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**
Able to carry out all normal activity without restriction	55	3	4	5	7	8	5	2	5	7	3	3	3

L3.1g – Final Stage Group at Diagnosis	Total	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
+ Stage 1	52	3	7	8	4	7	2	3	4	3	3	6	2
+ Stage 2	35	1	4	2	1	6	2	2	1	3	5	5	3
+ Stage 3	66	10	6	7	11	7	2	5	3	4	4	5	2
+ Stage 4	185	21	10	25	14	15	15	10	11	17	17	16	19
+ Unknown	89	13	4	6	16	3	10	7	3	5	5	9	6
+ Unstageable	2	0	0	1	1	0	0	0	0	0	0	0	0

Example Reporting & Feedback Schedule

Level 1 Report
NCRS Reporting Portal

Level 2 Report
NCRS Reporting Portal

Level 3 Report
NCRS Reporting Portal

NCRS

NCRS

NCRS

Process Data

| JAN | FEB | MAR | APR | MAY | JUN | JUL | AUG | SEP | OCT | NOV | DEC |

PAS

NHS Trust

COSD / Path

JANUARY Data
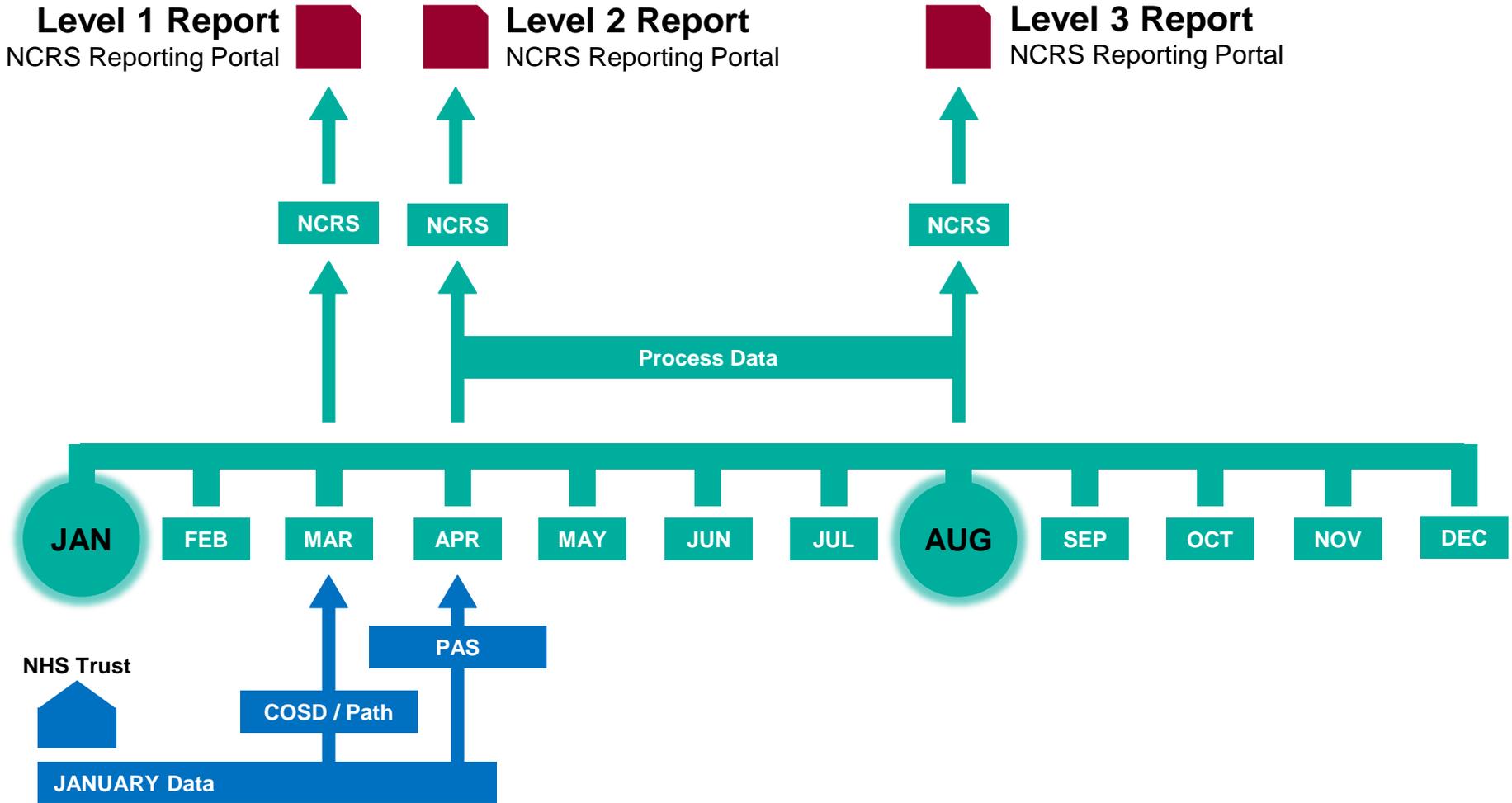
- The ability to view hospital data outside of the hospital setting

- There are different types of remote access:
  - Hospital PAS
  - Clinical letters
  - Oncology systems
  - Imaging (PACS)
  - Cancer Management systems

- National drive to gain access to all major hospital systems

- Relieves the data burden, allows NCRS to fill in the missing gaps

- Improves staging and data completeness

- Helps with clinical information for sites such as haem – clinical letters

Public Health England

	Imaging	Other Systems
Medway NHS Foundation Trust (RPA)	No	Yes
Dartford and Gravesham NHS Trust (RN7)	No	Yes
Maidstone and Tunbridge Wells NHS Trust (RWF)	No	Yes
East Kent Hospitals University NHS Foundation Trust (RVV)	No	Yes
Queen Victoria Hospital NHS Foundation Trust (RPC)	No	No
Surrey and Sussex Healthcare NHS Trust (RTP)	No	No
Frimley Park Hospital NHS Foundation Trust (RDU)	No	No
Ashford and St Peter's Hospitals NHS Foundation Trust (RTK)	No	No
Royal Surrey County NHS Foundation Trust (RA2)	No	No
Western Sussex Hospitals NHS Foundation Trust (RYR)	No	No
Brighton and Sussex University Hospitals NHS Trust (RXH)	No	No
East Sussex Healthcare NHS Trust (RXC)	No	No

Thank you for your contributions so far

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